ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN1826001

Exhibits: 0

Dated: 30 April 2019

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF GRO-B

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B. My address details are known to the Inquiry.

2. I am a widow. My husband died in 2000. My husband and I had three children together who are all now married. They were born in GRO-B

Section 2: How Infected

3. I received two blood transfusions; the first at Nottingham City Hospital on or around GRO-B 1972 and the second at Margate Hospital on GRO-B 1981. Both occurred as a result of post-partum haemorrhages GRO-B GRO-B

4. I went to Nottingham City Hospital on GRO-B 1972 to give birth to my first child, GRO-B I started to haemorrhage heavily after the birth and continued to do so for one week before I was eventually given a blood transfusion. I remember being progressively very unwell during this time and I did not know what level of blood loss was normal as this was my

first child. After the seven days had passed I collapsed. I was immediately transferred to another maternity ward. As I left the first ward I noticed it was labelled as a ward for unmarried mothers. I wondered if that was why I had been left bleeding heavily for so long. The father of our child and I were not married at that time. We married in 1973. He was there with me in the days after the birth but neither of us knew if how I was losing blood was normal. In the second maternity ward, which was for married women, I was told that I had lost a great deal of blood. The hospital staff told me they did not have any blood and so instead I would be given an iron transfusion. I was surprised by this because I knew that my blood type was the most common, 'O'. I had the iron transfusion and following it collapsed for the second time. It was only at that stage that I was told that I needed and would get a blood transfusion. It was very strange as the blood just appeared. I think that the blood transfusion was given to me on that same day. I had a fever following the transfusion, which they said was post-partum fever. I have since wondered if maybe the fever was from hepatitis C and whether this was possibly the occasion when I was given contaminated blood.

5. The second blood transfusion took place at Margate Hospital; now known as the Queen Elizabeth the Queen Mother Hospital, Margate, on GRO-B 1981 GRO-B I haemorrhaged severely following the birth and was taken immediately to theatre to deal with whatever was causing it. I asked the medical staff to carry out the sterilisation operation at the same time, which we had previously requested. I was given a blood transfusion in theatre. I know that this was the case because I was still receiving the blood when I came around from the operation on the ward. I was unwell after this experience too but as I had also had an operation I am unable to attribute my symptoms solely to the transfusion. Soon after this spell in hospital; maybe a month or so later if my memory serves me correctly, the local newspaper reported that blood contaminated with HIV had been given out at Margate Hospital. This obviously did not mean anything to me at the time.

6. I have not been able to locate my medical records concerning these births as

both hospitals have said they have been destroyed in line with NHS practice. Theoretically it is possible that I was infected during both transfusions in 1972 and 1981. I would like to point out that I noticed a great difference in the way that I was treated during the first and second transfusions. I have often wondered why there was such a significant delay before I was eventually given the blood at Nottingham City Hospital in the second maternity ward and whether the delay occurred because of my unmarried status. I have also wondered since whether there were two supplies of blood at that time; one supply which was unsafe or '*imported blood*' for the more undeserving and one which was safe or '*domestic blood*' for the more deserving. I know that the staff at Nottingham City Hospital seemed reluctant to give me blood.

7. I was not infected with hepatitis C (HCV) as a result of any relationship with another person.

8. As far as I recall, a nurse at Nottingham City Hospital may have told me that I would need a transfusion, but that was about it, information wise. I was unconscious at the time of the transfusion at Margate Hospital so I did not know that I was having one. I assumed I would however as I had visibly lost a great deal of blood on the ward. I was never told that receiving a transfusion might carry a risk of being exposed to infection. On both occasions I suffered very severe haemorrhages and I think that I knew that I would need a transfusion. I do not recall signing any consent form for the transfusions. (I had in ante-natal clinic signed for the sterilisation operation I believe).

9. I was infected with HCV as a result of being given blood.

10. Following the initial transfusion, I was keen to become a blood donor and as soon as I was able, perhaps a year later, I started to donate blood in Folkestone in Kent. I discovered I had HCV in January 1992 when the Blood Transfusion Service informed me by letter that they had detected HCV and that I should inform all of my sexual partners. This letter was very brief and left me in shock. It left me totally uniformed and with no guidance on next steps. The

letter informed me that my latest blood sample had shown that I had antibodies for the HCV virus and that my latest donation had not been able to be used.

11. As I have set out above, The Blood Transfusion Service sent me the brief letter which told me that the virus had been detected, that I should inform all of my sexual partners and consult my GP.

12. The Blood Transfusion Service wrote again soon after to invite me to their centre in London to explain the results more fully. I was told there that no-one knew very much about the virus, that it was very new. I was also provided with a leaflet which provided further information about the virus; including the tests for it and that it was only possible to test for antibodies, the risk of infection to others and development with treatments. I can make this leaflet available to the Inquiry if it would be helpful. At the London centre, I provided a further sample to them which tested positive. I recall that the virus was previously referred to as non-A and non-B hepatitis. My GP also knew very little about the HCV. This was to be a common response for quite a few years from other medical services I received. I received a further letter from the Blood Transfusion Service which informed me that I was no longer able to be a blood donor. This was obviously upsetting because I had been donating blood regularly for 19 years, from 1973. However, I also realised that by so doing I had been passing on the virus myself and infecting others. I have a great amount of guilt about this. My GP referred me to Kings Hospital, London. At first, their results showed up negative for me. I was told that the testing across the different testing centres was producing differing results. I provided a further sample which was found positive. I was told in a letter from Kings that it was not a virus to worry about too much. Kings Hospital took me on as a patient and as more became known about the virus they quickly started to treat me and share information. Initially, I just learned what I could from a couple of books I bought; the main information I retained was the sentence, '*Hep C patients don't live to an old age*.'

13. I was not given adequate information to help me to understand and manage

the infection at the start; but nobody knew much about it. I was told the basic information which was not to share toothbrushes and razors and to cover any cuts I had. I was also told that my whole family had to be tested in case I had infected them in some of these ways. The testing was carried out quickly and all tests returned negative results. The first letters that my consultant hepatologists wrote to me informed me that '*HCV often runs a very mild course*' and because my liver function tests at that stage were normal that I need not worry too much. One said he '*would be surprised if this positive test has any dire consequences.*' Perhaps that shows that knowledge of the true nature of HCV was lacking at that time. It had after all just been identified. Both doctors were trying to be reassuring and in the light of my normal liver function tests this was understandable. However, my liver test results soon started to become abnormal.

14. I found a letter recently from the Blood Transfusion Service, of 27 February 1992, to my GP, which, unlike their brief diagnosis note to me, was lengthy. In it they said my sample of 2 January 1992 was HCV antibody positive. But notably it stated that '*As routine anti-HCV tests on blood donations were introduced only in September 1991, we are still accumulating knowledge about tests and the implications of positive results.*' I have retrieved another letter which is dated August 1992 and which states that screening for antibodies for hepatitis C virus had been ongoing for one year. I have often wondered if they could have tested us donors sooner. I thought at the time that information was being provided to me as soon as it was known about but am not so sure about that now. It is I am sure different today. I would expect today to be given a lot of information and a prognosis and that my family and I would be offered counselling. But, back in 1992, it felt like it was an unknown virus. I think that I learned as the medical profession learned. Kings Hospital was excellent with me and the teams there kept me informed of what they knew.

15. My husband and I were devastated when we received the initial abrupt letter from the Blood Transfusion Service. It contained no information about the virus to explain what it was, it was very frightening to receive this information in this

way. I was angry and upset that there was an assumption that I could have had a number of sexual partners. Since it was addressed to me in my married name, this was, we realised much later, an extremely insensitive standard letter sent out to all, particularly because it advised me that I should advise **all** of my sexual partners, implying that I had more than one. This was upsetting for me and my husband because we shared a very committed and exclusive relationship. It was a rough introduction to the stigma that I was to face for so many years and a stigma that I believe HCV still carries today; that is, that one must have acquired it through drug abuse or sexual promiscuity.

16. I think I have indicated above the information I was given about the risks of others being infected.

Section 3: Other infections

17. I have been infected with HCV only.

Section 4: Consent

18. I do not believe that I was treated or tested without my knowledge or consent but I do believe that I was treated and tested without being given adequate or full information. This is because I believe I was not told about the risks associated with having a blood transfusion and when I was donating blood no-one expressly told me that my blood would be checked for viruses and illnesses. My blood was tested each time I attended to give blood and I assumed it was to test for iron content to ascertain whether I could actually donate. I do not believe that I was treated or tested unknowingly for the purposes of research, **GRO-B**

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Section 5: Impact

19. My HCV has had a profound effect on my mental and physical health and the effects have progressed as time has gone by.

20. Physically, I had fever after the first and second transfusions. These symptoms passed within about one week. I put the fevers down to post-partum symptoms. The most prominent physical symptom was and is the exhaustion, which would hit suddenly, and which made living with HCV very difficult. One minute I was fine and the next I felt really bad. Along with this was a feeling of having flu. This would happen often. With the exhaustion, it was impossible to do anything, even though I desperately wanted and needed to do things. I had zero energy until it passed. As a working mother I did not question the tiredness so I did not attend my GP complaining with the symptom. As I was at full-time work and with a family, dealing with these symptoms was very hard. I relied on my husband at home to help. When he died and the children had grown up and left home, I very often would come home from work and literally crawl up to bed, too tired to eat. I needed to sleep in order to get to work the following day. I started to get joint pains and was diagnosed with osteoarthritis in my hips and spine. I find it difficult to look back and attribute physical symptoms to the virus; I always put everything down to tiredness. In 2000, I was diagnosed with inflammatory arthritis of the chest wall; this was described by the consultant as '*immune-mediated and triggered by Hep C infection*'. I still have this condition. In 2010 I developed angina. This was not HCV related but it added to my general feeling of un-wellness. Mentally, there was guilt at being unwell and not coping as others did. I finally learned from my husband it was worse when I tried to hide it. He told me just to say, '*I feel unwell*' or '*it's a Hep C day*' (when I had been diagnosed) and he could take over instead of watching me struggle which he said had made it harder for him. There was

always the fear hanging over me also that I would not live to an old age. At the start of my treatment, the HCV clinics and wards were full of yellow skinned stick-like people with extended stomachs in late stage liver disease. This frightened me and, GRO-B who had to come with my husband once to visit me. It was as if I could see my future playing out before me. GRO-B Those images have never left me. That generation has died and treatments have been put in place so there became fewer like that to see. I always thought '*that will be me in the future*'. I put it out of my mind in between hospital visits but going there always reminded me of my possible mortality. I don't mean to sound dramatic by saying that. It is just how it was. I had no guilt at having been infected as it wasn't my fault. In the 21 years from treatment commencement, I didn't feel resentment or anger or self-pitying about being a victim. On the whole, I just got on with accepting I had it and fighting the darn thing as hard as I could. Once I was cured however in 2014, I finally got very angry about the whole business because I had lost the years from possibly 1972/ 1981 to 2014 to a virus which had taken over my life and my family's life. I had hidden as much as I could from my children but they were aware it was always there. My husband died in 2000 so never lived to celebrate with me at my cure. He just had the hard times. I found all of that incredibly hard to live with for quite a few months in 2015 when I was finally discharged from Kings after 23 years and could not share it with anyone. (I wrote a fictionalised story about it in the end just to get it off my mind). But it still saddens me today. They give me some money today to help. We could have so done with that when going through the worst of it together. That is a real lasting mental effect for me. I also still find it very hard to know that in trying to do good by being a blood donor, I would have infected /killed a number of people in the 19 years I was a donor. I try to tell myself that it was not my fault but it doesn't change the outcome. It would have been good if the transfusion service could have counselled us donors about this but it was never offered or spoken about. I try not to dwell on it.

21. Osteoarthritis, brain fog, severe fatigue/ exhaustion are all symptoms I have

suffered from the virus. These symptoms have very much decreased since being cured but I still find I get a great deal more tired than my peers if I have a particularly busy schedule any week.

22. I received four separate treatments for my HCV. The first treatment was in 1994 with interferon and lasted for nine months. I injected myself three times a week. It led directly to lifelong thyroid imbalance, for which I take medication. I was a '*non-responder*' to this medication. I was taken off it a few weeks early as by then I felt quite ill with it. Apart from the standard '*flu-like symptoms*', it frequently gave me low blood sugar levels. This side effect was not noted then but it is now. In 1999 I started my second treatment. This time I was administered a Ribavirin and Interferon combination treatment. I could only tolerate the treatment for six months because of the side effects. Ribavirin started my '*brain fog*', when I began to have sudden memory lapses. The consultant warned me when he started me on it that this would happen. Brain fog, is a known side effect. The symptom would serve to make me feel confused often and for a few minutes at a time I could become so disorientated that I would not know where I was or why I was in a place. I am immeasurably better but still get exactly the same momentary brain fog and disorientation; this HCV brain fog is quite different to my ageing brain's '*senior moments*'. It was a horrible drug for me. In November 2012 I had to have a further course of Interferon and Ribavirin for a period of three months so that I could qualify for any possible future clinical trial. This was because I had not previously had Pegylated Interferon before: a once per week injection with slow release, which I needed to have tried before any clinical trial. I was a non-responder to this

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GRO-B By October 2014, I had been clear of the virus for a period of 12 months. In May 2015, I was declared HCV-free and discharged from the hospital clinic. I had been attending the liver clinic at Kings for 23 years. I have not so far suffered a relapse.

23. I was lucky to be referred to King's Hospital. They allowed me to remain with them even though we moved up to GRO-B for a while. They were very clear at all times about treatments that were available and suitable. I was with them for 23 years until in 2015 when I was discharged, cured. I feel I was offered all that was available and experienced no obstacles. I remain very grateful to them. I now try to follow up with my GP just to keep an eye on my liver function. The GP is usually reluctant to be asked by a patient to have the tests but they do them roughly once a year.

24. There is no other treatment that I feel ought to have been made available to me.

25. The mental and physical effects of the treatments were significant. They often made the underlying symptoms of the HCV much worse and brought about new symptoms that I have had to endure even to today. For example, I developed an underactive thyroid as a direct result of the first nine month treatment with Interferon. The Ribavirin combination treatment gave me severe brain fog and though the problem has improved somewhat, it has not disappeared despite finishing the medication five years ago. One set of hospital clinic treatment notes from when I was on that combination medication in January 2013 said '*...she recently had a chest infection but it is now cleared up. She suffers from continuous all over itch, nausea, hip and back pain, hair-thinning and is feeling depressed. She is aware that these side effects can all be attributed to her current treatment...*' This is why I welcome the Inquiry, which will show people just how much our day to day worlds were affected by the virus and its treatment. Subsequent to the Clinical Trial treatment in 2013/14, I was left with a very much heightened feeling of anxiety about the safety of others, particularly children. This affects me with anyone's children. When I am randomly out and about, I am always fearful that a child will run into a road or fall in the pool. I have learned to look away from them to deal with this anxiety. This has caused arguments with my children when I am over protecting their children or watching them anxiously. It makes me feel uncomfortable too. I can rationalise all of this but cannot stop feeling it. I do

not know exactly which medication caused this effect as most of the drug trial medicines were unnamed. I, and an HCV friend feel the long term effects of the virus or the medicines have remained with us to an extent, despite being cured. The drugs came with awful side effects. It was horrid injecting oneself with Interferon; for example, knowing what you were putting in was going to make you feel like you had a bad bout of flu and just as you began to feel well again it was time to inject another dose. In later years the Pegylated interferon managed to avoid those awful highs and lows of the treatment so it was better. Other drugs gave rashes and made you feel depressed or just really ill. The Kings team were excellent at helping with any medicine which could allay side effects. In the early days following on from my diagnosis in 1992, the liver biopsies that I had to endure were very painful both during and after the procedures. I had five of these in total: in 1992; 1995; 1998; 2002; 2007. The medical team went in blind and sometimes caught the diaphragm, which caused shoulder pain. Sometimes, they had to go in twice if they missed. This is not a criticism of their skill just how it was. Later, they began to do the biopsies with the aid of an ultrasound which made them more accurate and finally they began to do fibroscans along with an ultrasound to check for fibrosis which together gave them a good reading without the need for an invasive biopsy. Mentally, it was hard having all this done to you when you had been given the virus in the first place. At first, the biopsies required overnight hospital stays. I used my half term holidays to get treatments and appointments done in order to lessen any impact on my work. I am sure all this impacted on my children in a number of ways by not just seeing me physically unwell but using up holiday times with this. All of this made me feel guilty.

26. My infected status has impacted on my treatment for other conditions. I have always had to declare to medical staff my infected status whenever I have had to attend a hospital. I spent years with people telling them how I acquired it. I did not feel I had the need to explain how I had become infected but I was always asked. I felt an obligation to always declare it and a stigma after having done so because of always having to explain how I acquired it. One felt they automatically assumed drugs or sexual promiscuity were the cause, which was

impertinent, unfair and very hard to live with on a daily basis.

27. At first, my husband and I were advised to use condoms as he wasn't infected, which we didn't like particularly because I was sterilised anyway. Then we were told it was OK to not use them. In the house, I kept my toothbrush and razor out of everyone's way and kept away from everyone if I cut myself. So HCV had a constant if unspoken presence at all times. I explained all I knew about the virus to the children and did everything I could to shield them from the full impact of the virus on me, so they wouldn't be worried. I have asked them to write their own accounts, which they are providing to the Inquiry. I have been saddened to read of the impact that this virus did have on them and how they were not previously prepared to share their experiences with me for fear of upsetting me. I feel devastated by this. One thing that stands out in their experience of this is how odd they felt the separation of my toothbrush and razor from theirs to have been. They were all rather worried about this. They did not like to share my drinking cups either. I always thought I was very good at hiding and managing this with them. What I thought was routine in my house was actually causing concern and upset. I guess my Sharps disposal box in the bathroom for my needles in the early years wasn't too subtle. My husband found the burden of living with it difficult. I eventually asked him to share it with a friend; he found this helpful but I don't know what he really felt about it. GRO-B GRO-B GRO-B We both knew anyway we faced the prospect of an earlier death for me, and that was a real shadow on our private world. Mortgages and insurance were tricky for us because of my HCV which added to our financial stress. Socially HCV wasn't a problem. We either never spoke about it to people or mixed with close friends who knew and were OK with it.

28. Initially, I felt really bad having a sticker put on my blood samples to the effect

of '*Danger. Contaminated blood.*' They contained a skull and crossbones picture as well I think. I can't remember the wording exactly. GRO-B

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GRO-B Sometimes, I had to remind hospital workers to put the stickers on, which was embarrassing. At first, I often wanted to walk into the smart hospital café and deliberately drop my sample on the floor in front of people. That might sound stupid but I felt by being so clearly labelled that I was unclean. Then you get hardened and learn to live with it. The constant stigma of HCV is the hardest mental effect. So many people felt they had the right to ask me; often loudly and publicly, how I'd acquired HCV. I was very sure too that when I informed my school employers in 1994 that I had it and was about to start treatment, and soon after they said I would have to go part-time as I was unwell, that it was the actual nature of the illness which made them want me out. They would never admit to this though. The stigma meant you couldn't say to anyone, '*I feel a bit ill today. I've got Hep C.*' You might as well have said you had medieval leprosy. When it came to my final drug trial at Kings and my initial reluctance to engage in yet more awful medicine which might not work, my lovely consultant won me over with a grin and the words, '*What have you got to lose? Living with the stigma for starters.*' He was right. I went ahead and they cured me and I have so loved not having that condition and having to defend myself always. People feel sympathy if you have a normal illness. They can be very self-righteous if you have HCV or HIV; they start washing their coffee cups and pointedly never touching yours.

29. Education, work-related and financial effects:

30. I was infected as an adult so school and university was not a problem. When I took my first Masters though I was still on my first nine month treatment with Interferon and it was very hard to keep up the pace. I broke down at one point with having to cope with it all as the medication did not agree with me. But, I managed to finish the course successfully.

31. In 1994, the school I was teaching at full-time told me I had to go part-time due to ill health. I had just started my first treatment. I had previously told them I might feel a little unwell. They had agreed that was OK. I did not take time off but they saw me a few times feeling unwell. I had told them how I got the HCV. I always felt they objected to the virus itself as they showed no normal sympathy. When I told them they could not make me go to part-time work on the grounds of ill health they immediately gave me redundancy notice and prepared a case against me claiming I was an inadequate, poor teacher. I had worked for the school for approximately 12 years. I took them to tribunal and won a unanimous decision for constructive dismissal. Much of the employer's tribunal statements revolved around the fact that I had HCV and was undergoing treatment. It was clear that HCV had been a major factor in my redundancy. The timing of everything meant that I could not get another job in time for the new school year. I had been working in London where there was a lot of competition for jobs; I was 44 at the time and so was more expensive than younger teachers. I decided I would try to start a private language school in a new house and new area as no school teaching posts were to be found. My husband and I took the decision to sell up, to relocate to a new house GRO-B GRO-B and move our daughter to a new school. I began to try and build a business up and at the same time enrolled on a Masters degree to improve my future employment chances. My business did not take off but I landed a school post the following year. I worked until 2013. I never told any employer again that I had HCV. I finally retired from work a couple of years earlier than I had intended to, aged 63, as it was getting too much for me. I was too tired. My Ribavirin treatment in 1999 and again in 2012 also gave me brain fog, which made it hard to keep a constantly sharp mind at work.

32. The financial effects of the house move to GRO-B described in (b) were huge as I lost my teaching income for a year and we had to take out an expensive bridging loan to cover our expenses of a fast move GRO-B My husband could not move his job straight away so we had to rent a flat in GRO-B for me and my daughter while the sales went through so she could continue her GCSE year properly. As stated before, mortgages,

mortgage protection schemes and insurance were more expensive with HCV.

33. Each of my three children is providing a statement to the Inquiry to include how this has impacted upon them. I can't ask my husband now what it was like but it must have had a tremendous impact on him, because from the start of my treatments I was frequently unwell due to the side effects of drugs. Financially, we needed my full-time income as well as his. There was no chance of me stopping work or cutting hours. This led to tensions between us due to money problems. Our move to GRO-B when I was made redundant and couldn't get another job was a huge risk financially but we felt it was our only solution to me being unemployed. There was a tremendous stigma to HCV so he must have felt it was like hiding a guilty secret when people asked how his wife was. I eventually persuaded him to talk to someone just before he died to alleviate some of the stress. HCV affected our home daily life. I wanted to play down the potential seriousness of it. But, my children weren't stupid. My silence on it made it worse for them they say in their statements. With hindsight I should have run all my ongoing updates on health, after clinic visits with them so they could know I was doing OK despite feeling unwell. In the house we didn't share cups and razors and toothbrushes were kept out of the way and if I cut myself I disappeared to bandage it up. They apparently hated all this. HCV was the unseen and unspoken but greatly feared presence in our house. If I'd known I was to be a survivor it would all have been so very different. It clouded my children's and husband's lives. I feel very guilty about that.

Section 6: Treatment/Care/Support

34. I do not believe that I have faced difficulties or obstacles in obtaining treatment, in consequence of being infected. I have not received any care or support such as counselling. Perhaps this was because I was diagnosed in the early years of knowledge about HCV. I have had treatment for my osteoarthritis with pain killers and injections but I am not sure anything can treat the exhaustion. I have nothing but praise for Kings and I believe they did the best for me. They

handled all of my hepatitis treatment. I have never consulted my GP about any of it.

35. Counselling or psychological support has not been made available to me in consequence of being infected. I have had none whatsoever. GRO-B

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Section 7: Financial Assistance

36. I have received financial assistance from Skipton and EIBSS Funds.

37. I became aware of the Skipton Fund only through a fellow HCV clinic friend in early 2014 and applied for it. I was surprised to learn recently that it had existed since 2004 and that I could have benefited from it beforehand, but I did not know about it.

38. I received a one-off ex-gratia Stage 1 payment of £20,000 from the Skipton Fund on 1 May 2014. They contacted me in 2016 about the new annual Skipton Fund Stage 1 payment amounting to £3,500 (inclusive of £500 winter fuel payment) starting in November 2016; the payments were made on a monthly pro-rata basis. When I cleared the virus finally in 2015, I enquired if I was still eligible for these new payments and was told that I was. The Skipton Fund informed me in 2017 that from November 2017, the payments would be made by the NHS Business Services Authority (NHSBSA). This body informed me in December 2017 that there would now be a Special Category Mechanism (SCM) payment which I could apply for if I had lasting difficulties from either the virus or treatments. This meant that Stage 1 HCV patients would be placed on a par with Stage 2 cirrhotic HCV patients. To access this SCM payment I had to make an application. I had to do this in February 2018 and if

successful, the payments would be backdated to October 2017. My application was successful and I moved onto the higher annual payment of £15,655 per annum. In April 2018, these payments increased to £18,000 per annum. I also receive the £500 fuel allowance and without the need to re-apply. In August 2018, the England Infected Blood Support Scheme (EIBSS) sent out application forms for income top-ups, which depend upon one's other income. My payments were increased by a further £134 a month, bringing the total current annual payment to £19,608, plus the £500 fuel allowance.

39. I think I have covered this fully in (b) above. The application process has required a lot of documentation but I have accepted that it is necessary. I have always asked my consultants at Kings for assistance with this as I have never gone to any GP with HCV related issues so there is little on my GP records about it.

40. My original Skipton Fund application was initially refused as neither of the NHS Trusts (Nottingham and Margate) which dealt with my confinements and blood transfusions had records of me as a patient; it is NHS practice to destroy records after a period of time. Though I sent their letters stating this to Skipton I still had to prove somehow that I had received transfusions. A large part of my NHS records are incomplete; the records I do have do not show that I received blood transfusions. Kent NHS has no record of me as an NHS patient there with a GP or hospital despite me living GRO-B GRO-B and being registered with GPs. My current GP medical records do not show that I had a transfusion in the Nottingham area in 1972 either. My GP said often a hospital would omit to pass on information to the local GP. I finally found in my possession a Co-operative record card for maternity patients for the birth GRO-B GRO-B which had written at the bottom the fact that with my first son I had had a post-partum haemorrhage and received a blood transfusion as a result. Skipton accepted that. It was a one-liner and written on a scrap of paper. If I had not retained that piece of information, through my own record retention, I would not have been able to access the Fund. I still have no evidence of my

transfusion in 1981.

41. There were no preconditions imposed on making an application or in receiving the financial assistance.

42. Since Skipton accepted me onto the scheme, I have been informed at all stages of what I am entitled to; however it is incomprehensible how the Fund was not made known to all HCV patients automatically when it was set up. Skipton, NHSBSA and EIBSS schemes have been very efficient. Personally, I find it hard to accept their money now I am not HCV positive but they have said all along that this is correct. We suffered so much from financial hardship when I lost my job all those years ago and we moved, so I try to tell myself that in some small way it makes up for those hard times. I have a deep resentment that my husband was not able to benefit from the financial assistance that has been made available to me particularly because we so desperately needed it in earlier years.

Section 8: Other issues

43. There are no other issues in relation to which I have evidence which would be relevant to the Inquiry's investigation.

44. I have documents relating to my initial diagnosis, medical treatments, NHS records deletion, applications for financial assistance that may be relevant to the Inquiry's Terms of Reference. I can make these records available to the Inquiry should it deem it helpful for me to do so.

45. I am hopeful that the Inquiry will investigate rigorously whether any bodies knew about HCV and HIV contamination of blood but still continued to use it. If negligence is proved, then I would expect those bodies to be held to account. I feel the damage done to lives and the loss of lives should be properly recognised. I am hopeful that the Inquiry will serve to inform people of what happened and that people will begin to sympathise with those who have been

infected instead of stigmatising them. I am hopeful that the Inquiry will ensure that that those needing and deserving of compensation will receive it and those still needing counselling will receive it. I am hopeful that the Infected Blood Scandal will be recognised for what it is: a tragic taking of people's health and lives.

46. I was told in Nottingham City Hospital in 1972 that there was no blood available when I needed a transfusion. I am not sure they were telling me the truth. Furthermore, I have always wondered whether when I was finally given the blood transfusion it was from a source abroad and of inferior quality because I was considered morally underserving to receive blood from a domestic source, because I was an unmarried mother. In 1972, unmarried mothers weren't treated well. They didn't matter. I would like the Inquiry to consider whether there were times when two sources of blood were available (domestic, better quality blood and international, inferior quality blood) where decisions were made based on a moral hierarchy as to which source patients were given.

47. There are many missing details in my NHS medical history. I have no medical records GRO-B, even though I supplied GP addresses to the NHS Hospital when I was treated there. In addition Nottingham City Hospital has no record of me whatsoever, even though I have provided them with details of my unmarried name GRO-B According to my current GP records I have only two, not three children and hospitalisation in recent years is not included.

48. In terms of how I feel I was treated as a person who had contracted a virus; I feel I was treated very well by medical professionals, although I have always avoided taking HCV issues to a GP and have instead dealt with these issues at the hospital. I have moved around a lot but no GP has ever asked or understood any of the HCV matters. At the start of my journey with this, I did have one GP receptionist call out to the whole waiting room, '*who's here for the hepatitis C test?*' That wasn't good. I have always felt that I have been

treated very well by staff working for the charitable trusts established for victims of infected blood.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed: **GRO-B**

Full name: **GRO-B**

Date: 30/04/2019